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Vol 10, No 2 (Summer 2011)

The Ultimate Expert: A Patient's Perspective

Section Editor: **Myung H. Park, MD**

Jessa Scott
Former PH Patient
Age 22 years

In June of this year, at age 22, I had the opportunity and privilege to captain a team of walkers and runners in a 5K event to support organ donation awareness. Together with some of my closest friends and family, I participated in a celebration of my second chance at life. As a survivor of pulmonary arterial hypertension (PAH) as well as an organ transplant recipient, I experienced for the first time the ability to participate in an event of this type. It was previously beyond comprehension and physically impossible for me. Physicians informed me that PH worsens over time and can be life-threatening when the pressure in a patient's pulmonary arteries rises to dangerously high levels, resulting in strain on the heart. However, when I was diagnosed with PH as an adolescent, I still felt healthy. Nothing could have prepared me for

the impact that PH would have on my life. There is no cure for pulmonary hypertension, but many patients find varying degrees of success with the medications available to address or alleviate the symptoms and improve quality of life.

Possible treatment options included medications, oxygen, and a path I never originally considered: lung transplantation. In the beginning of my treatment course, medications such as Revatio, Letairis, Ventavis, and Coumadin did a great job, and I felt the air easily returning to my lungs and hoped for improvement. Unfortunately, these medications still did not lower my pressures to a medically-acceptable level, so I continued oral therapy and began subcutaneous treatment with Remodulin. Still the symptoms and the high pressure persisted; so we remained as aggressive as the disease itself and tried the commonly proclaimed “gold standard” therapy, Flolan (IV epoprostenol). Treatment with this medication was the most invasive of all, with the opportunity for infection at the central line entry site, but it was also the most beneficial at that stage of my disease.

Although all of these treatments were effective to some extent, they never eliminated my worry or fear of carrying out any activity. The “albatross around my neck”—the anxious, always-present panic and fear associated with struggle and shortness of breath to near suffocation— remained with me at all times. I would constantly question: “will there be stairs?”, “how far do I have to walk?”, “where can I stash my cache of back-up medication?” No words can fully describe the pain and physical burdens imposed on my body every day from side effects of Flolan and other medications—and of this disease. Pale words like crippling back and chest pain, massive body aches, blinding headaches, nausea, vomiting, and diarrhea are accurate names of some common symptoms, but don't come close to reflecting my life—or the lives of other PH patients that progress to this stage.

Despite the physical toll, at the final stages of my disease the toughest struggle was with the fears and emotions that would not let up. The resentment, loneliness, and ostracizing resulting from being regularly plucked out of school and my social life to address my physical limitations were just as difficult to deal with as the disease. There was also the embarrassment from often being stared at in public and knowing that I am no longer just a 22-year-old girl, but a wiry mess of oxygen and intravenous medication tubing. Some patients will be lucky enough to be prescribed less invasive oral or inhaled medications and remain stable with that treatment; others might respond best to subcutaneous or intravenous therapies. For the few like me who have tried all of the above and still need a transplant, we must remember that we are lucky, too. We are all blessed because we have more options and opportunities in 2011 to minimize our symptoms and struggles.

This disease often debilitated me; yet I realized after my lung transplant that it also educated me far more than I could have ever imagined. While I will never actually be grateful for having acquired these health problems, the experience of living with pulmonary hypertension has taught me to find strength and hope despite any circumstance. I've found courage and an empathy that I didn't know I possessed before this experience. My skin is now clear and not marred by red splotchy irritation. I no longer carry my brick-sized, battery-powered pump companion or have oxygen tanks to contend with. And actually, the most amazing and liberating action and feeling of all: a deep, respirating, life-embracing breath. The past couple of years before my operation, I would constantly feel the medical side-effects and the shorter-and-shorter breaths, and gasp for breath as if I were running. However, I was not running—and, in fact, running or even jogging had been out of the question for many years.

Now, just a few months shy of my 1-year anniversary of a lung transplant and ECMO course, I can run, and jump, and race up flights of stairs. While for most people these would seem like mundane activities, I know it's a miracle. With a fuller appreciation for life and new lungs, I have the ability to live a fuller, richer life. Now, in the prime of my health and of my life, I am lucky to have the opportunity to plan to run more races and advocate for causes I support. Further, I happily report that I love the maturity and responsibility PH gave me, and the independence and freedom the transplant has given me. As I learned from these two hurdles combined, I love and appreciate every day I am given to have another chance at life.

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